

Indiana Deafblind Services Project

DEAFBLIND FOCUS

Volume 23 | Issue 1

Summer | 2013

Father's Day...

Living a Different Kind of Dream

(The following article was written by an Indiana parent of a child who is deaf-blind.)

Up until about a year ago, when someone from my past would ask me what I've been up to I would always respond with "I'm just living the dream". It was true. We *were* living the dream. Before Daisy was born we were that couple who went on weekend getaways and vacations with our dog and cruises with our friends. After we had Daisy we were that family who went on frequent weekend getaways, day trips, and vacations with our adorable little daughter. We couldn't wait until Daisy was two so that we could take her on her first cruise.

Since having Aria we've become that family who everyone pities. We're that family who can't go to the grocery store without fielding a million questions. We're that family who is afraid to go on a vacation. We are that family who won't go visit the grandparents two states away because we are afraid our child might get sick and need medical intervention that can't be provided locally. We are that family who will never again go on a cruise because our child is too medically fragile to be floating in the middle of the ocean, far away from a surgical suite. We are that family who will never again leave the country because we always need access to the best care at a moments notice. We are that family whose dream has been shattered. Most



Daisy and Dada had fun in the lazy river!

days, if you were to ask me what I've been up to, I'd reply, "I'm just living a nightmare".

With that said, I still realize we are quite lucky. I'm slowly coming to terms with the fact that I need to redefine "the dream". We can still live the dream if we're willing to change our expectations. I'll get there. I need to get there for my family.

So, over Father's Day weekend Kevin and I decided to get back to living a different kind of dream by going on our first family getaway since Aria got home from the hospital. We wanted to stay close to the children's hospital just in case so Kevin booked us a room at one of those hotels with an indoor water park that happened to be within a couple of miles from Aria's doctors. Daisy loves splashing in the water and Kevin loves slides so it was a perfect choice for a Father's Day getaway.

We were only going to be gone for two nights but packing was scary. I was so afraid I was going to forget something. Aria requires so many supplies and it's not like it's stuff that you can

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*My girls and me -
living a different kind of dream*

just head to the local pharmacy to pick up. If you forget something you are screwed. Once packing was completed I had one small suitcase full of diapers and clothes for the whole family and three other bags full of supplies for Aria (drugs, food, tubes, pumps, syringes, aspirators, etc). I can only imagine what the hotel staff thought as we checked in for two nights with our bell cart full of four bags, a feeding pump bag, and cooler, a pack-n-play, and a double stroller. They probably thought we were high maintenance. They would be horrified to find out just how high maintenance we really are.

We checked into our room and immediately headed to the indoor water park. On the first day Aria was really frightened by the water. Even though she and I weren't able to spend as much time in the water as I had hoped I loved watching Kevin and Daisy play.

The second day I took my time getting Aria into the water. Guess what? When I really focused on her and followed the cues she gave, we were able to get all the way into the pool. In fact, Aria loved the lazy river. By the end of the second day I could simply hold my hands under her head to keep her face out of the water and let her float along the current on her back. She was so relaxed in the water. I think she cried less that day than she has on any other day of her life.

Between multiple trips to the pool we went out to eat, ordered room service, and just hung out in our room. Our first trip as a family of four was more low-key than any trip we had been on before but I wouldn't change it for anything.

It was the perfect getaway for our family....creating a new kind of normal...living a different kind of dream...



*Aria looked fabulous
in her swimsuit and shades!*

*"It was the perfect getaway for our family....
creating a new kind of normal...
living a different kind of dream..."*

Indiana Deaf-Blind Grant Award

The Indiana Deafblind Services Project, a federally funded grant through the Office of Special Education Programs (OSEP), will be completing its five-year award on September 30, 2013. We recently completed an application for a new grant award for the 2013-2018 cycle and are awaiting notification of funding.

Thanks to those of you who provided us with letters of support and commitment. If the grant is awarded, the project will be sharing its new five-year plan and targeted initiatives in a future newsletter.

If you have worked with us in the past, or would be interested in forming a new partnership to improve services for Indiana students who are deaf-blind, we would love to hear from you!

Email us at
db@indstate.edu

Indiana National Deaf-Blind Equipment Distribution Program Provides Communication Technology for Persons who have Combined Vision and Hearing Loss

Indiana State University Leads Indiana's iCanConnect Campaign

Many Americans who have combined hearing and vision loss are now better able to connect with family, friends, and community thanks to the National Deaf-Blind Equipment Distribution Program (NDBEDP). Mandated by the 21st Century Communications and Video Accessibility Act (CVAA), the Federal Communications Commission (FCC) established this program in July 2012 to provide support for the local distribution of a wide array of accessible communications technology. Funding is provided to entities in each of the 50 states to conduct this program.

In Indiana, the National Deafblind Equipment Distribution Program is a partnership between Indiana State University and Perkins School for the Blind. It is designed to effectively provide equipment and training to persons who are deaf-blind and whose income does not exceed 400 percent of the federal poverty level.

Over the last year persons across the state of Indiana, ranging in age from 14 to 80, have received equipment and software that has improved their ability to connect with others and access communication avenues that most of us take for granted.

The goal of the program is to help ensure that people who are deaf-blind have the communication access necessary to be safe, hold a job, manage a household and otherwise contribute to their communities.

Through the website www.iCanConnect.org/Indiana, individuals, their family members or caregivers will find information about the program including:

- who qualifies,
- what types of equipment are available, and
- how the equipment is being distributed and installed.

NDBEDP Success Stories

~ A deaf-blind gentleman from the Pacific northwest was hesitant to enter into the world of iOS devices - the mobile operating system for Apple-manufactured devices - nor could he afford to purchase them! When he qualified for the NDBEDP, he received an iPad along with a braille display, and quickly mastered them both. He now can text his friends, check his email, and re-connect with his contemporaries. "I can be assured that my communications with (my friends) are without errors. Thank you NDBEDP!"

~ A hard of hearing woman with macular degeneration in the Midwest felt left out. During the day, her husband and teenagers all communicated by texting on their cell phones. She had received a Captel phone with a larger font and better contrast for calls made at home, but wanted to be able to stay in touch with her teenagers and husband when she was away from home or at work. Now, thanks to the NDBEDP, she has a tablet that is large enough to see the text size and portable enough that she can take it with her wherever she goes. She can be in constant contact with her family once again – something most people just take for granted these days.

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CONNECT! a publication of the
Helen Keller National Center,
Summer 2013 Issue.*

For questions about the iCanConnect
campaign or for application information,
contact Lisa Poff at
1-800-622-3035
or email Lisa.Poff@indstate.edu.

A Heartfelt Farewell to Karen Goehl



Karen Goehl has spent the last 27 years working in the Blumberg Center. During this time Karen has been responsible for securing funding instrumental to the continuation of the center. Most recently she has served as Director of the Indiana Deafblind Services Project, Promoting Achievement for Students with Sensory Loss and the FCC Indiana Deaf-Blind Equipment Distribution projects. You can send your best wishes to Karen by email at Karen.Goehl@indstate.edu.

Indiana Deafblind Services Project Deafblind Focus Volume 23, No. 1

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This publication is made available by the Indiana Deafblind Services Project, through the Blumberg Center for Interdisciplinary Studies in Special Education, located at Indiana State University, with support from the U.S. Department of Education, Office of Special Education Programs under grant # H326C080017 and the Indiana Department of Education, Office of Special Education.

The views expressed in this newsletter do not necessarily reflect the opinions of either the U.S. Department of Education or the Indiana Department of Education and no official endorsement should be inferred.



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